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The State of Management of HAE in Central America and Caribbean Countries: Results from a Patient Advocacy Lead Survey

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HAE International (HAEi), the global umbrella organization for the world's hereditary angioedema (HAE) patient organizations.

Rationale: HAE management and access to medication vary around the world. This State of Management of HAE research focuses on the current treatment situation and its impact on people with HAE in Central America and Caribbean countries.

Methods: A patient leader from HAEi member organizations in 7 Central America and Caribbean countries participated in a 28-question online survey. These leaders responded on behalf of people with HAE in their country. Responses were collected in April 2022.

Results: Across the countries, respondents estimated HAE diagnosis vs expected HAE patient numbers vary from 1% to 86%. 2/7 countries have access to a form of modern medication. 5/7 countries rely solely on fresh frozen plasma, steroids, or tranexamic acid. HAE has a high impact on people's lives (scale 1-10; 1=no impact, 10 =major impact, 6/7 rated 8+). The majority (4/7 countries) ranked the likelihood that HAE patients can either (1) live a normal life and (2) fulfil their life's potential without access to access to medicine as very low (5-point scale; very low to very high). The most significant challenges identified for people with HAE were availability and funding for modern medications licensed for HAE. 6/7 countries ranked their Government's priority of rare diseases as 10 (10 diseases/disease categories; 1=highest priority, 10=lowest priority).

Conclusions: HAE patient leads, who ultimately represent more than 1,900 people with HAE report that HAE is under-recognized, under-diagnosed, and under-treated across the region. An important step toward improving the lives of people with HAE in Central America and Caribbean countries should involve (1) each country increasing awareness raising activities that includes engaging with health ministries and (2) developing data that characterizes the burden of illness and value of modern HAE therapies.